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GROUP WORK WITH PARENTS OF CHILDREN WITH LEARNING DISORDERS.

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SINCE THE PARENTS OF CHILDREN WITH LEARNING DISORDERS FELT ISOLATED FROM THEIR CHILDREN, THE PSYCHIATRIST IN CHARGE OF THE NORTH SHORE MENTAL HEALTH ASSOCIATION DECIDED GROUP WORK WITH THESE PARENTS WAS NEEDED. FROM THE EXPERIENCES OF WORKING WITH SEVERAL SUCH GROUPS IT HAS BEEN DECIDED THAT (1) A GROUP SHOULD BE COMPOSED ONLY OF PARENTS WHOSE CHILDREN HAVE BEEN PROFESSIONALLY DIAGNOSED AS HAVING A PERCEPTUAL PROBLEM, (2) THE GROUP SHOULD MEET EVERY OTHER WEEK FOR 8 SESSIONS FOR A PERIOD OF 1-1/2 HOURS, (3) A FEE OF \$10 SHOULD BE CHARGED, ALTHOUGH NO ONE WOULD BE DENIED ADMISSION BECAUSE OF INABILITY TO PAY, (4) GROUP SIZE SHOULD BE FROM 10 TO 12, (5) THE CHILDREN REPRESENTED SHOULD RANGE NO MORE THAN 4 YEARS IN GRADE LEVEL, AND (6) A GROUP SHOULD BE COMPOSED OF PARENTS AT THE SAME LEVEL OF KNOWLEDGE OR LACK OF IT CONCERNING PERCEPTUAL HANDICAPPING. THE GOALS OF THESE GROUPS HAVE BEEN (1) TO GIVE FACTUAL KNOWLEDGE ABOUT A KIND OF DIFFICULTY WHICH IS LITTLE UNDERSTOOD, (2) TO PROVIDE A PLACE FOR DISCUSSION OF FEELINGS CONCERNING THE CHILD, AND (3) TO PROVIDE A CLEARINGHOUSE WHERE USEFUL TECHNIQUES OF MANAGEMENT CAN BE SHARED. EVALUATIONS MADE BY MOST OF THE MEMBERS OF THE GROUPS HAVE INDICATED THAT THESE GOALS HAVE BEEN MET WITH SOME DEGREE OF SUCCESS IN ALL AREAS. ALSO, IN SPITE OF THE FACT THAT NO PATTERN OF PERCEPTUAL DIFFICULTY IS LIKE THE NEXT, CERTAIN GUIDEPPOSTS TO HELP PARENTS HAVE BEEN FORMED BY THESE GROUPS. INCLUDED ALSO ARE QUOTATIONS TAKEN FROM A PARENT'S EVALUATION SHEET TELLING WHY THE GROUP WAS BENEFICIAL. (CO)

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Group Work with Parents of Children

With Learning Disorders

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If there is any group more confused and perplexed about themselves than that group we call "perceptually handicapped" children, or any one of a dozen other labels, that group is the parents of these children. The process of refining diagnostic, treatment, and educational techniques for these children has been and still usually is a slow and torturous process, the responsibility for which has been shifted from educators to psychologists to psychiatrists to neurologists and too often back again. Only in the past five years has its pace been quickened; even that quickening is uneven across the United States, and in many places the speed has not been matched with accuracy and with integration of professional efforts.

If these things are true--as they seem from our point of observation to be--it is an equally uncomfortable truth that counselling with the parents of these children has been almost non-existent. Nowhere in the literature concerning perceptually handicapped children have I found any accounts of group work involving these parents, though, of course, there may be such accounts which have escaped my notice.

My own experience in the field began in 1962 when the Irene Josselyn Clinic of the North Shore Mental Health Association began an experimental program of testing and treatment with a few children who had been referred for psychiatric diagnosis but were then found to be perceptually handicapped. When it was begun, there was no thought of including a parents' group in the range of services being offered. Some of the parents were being seen on a regular basis by Clinic social workers in an individual relationship. Others had infrequent, unscheduled conferences with their child's tutor-therapist, when one adult or the other felt the need for such a contact. Quite early in the course of this project, the psychiatrist in charge, Dr. Mary Giffin, Medical Director, felt that there was a need for group work with the parents. In spite of, or perhaps because of the attention being given to their children, the parents felt neglected, isolated from their own problem. It was almost as if, in what they considered an act of surrendering their children to the therapeutic and/or education activities being carried on by the Clinic, they themselves were giving up some of their parental rights while maintaining the grueling and sometimes heartbreaking responsibilities for the children. The feeling was, "I've lived with him all these years; I've cried over him and defended him, he has caused me pain and joy and here are a group of strangers talking about him in words I never heard of, and not even telling me what it's all about or what they do with him behind those

closed doors." Clearly, the situation was one fraught with conflict. The Chinese symbol for conflict is composed of two characters, one standing for danger and one for opportunity. Rather than give in to the one standing for danger, in this instance, we chose to emphasize the one standing for opportunity.

As I look back upon that year of 1961-62, I am amazed at our own temerity in blithely forming a parents' group to meet the need we saw. We had no guidelines, the leader had only rudimentary, quickly acquired and thus superficial knowledge of perceptual handicapping. I can say this with ultimate authority--I was the leader. What I did have was many years of experience in the field of parent education, group work and teaching. What I immersed myself in for weeks was all I could find about group work with parents of handicapped children. Much of this was useful; the parallels between living with a physically handicapped or retarded child were there and they were helpful, but like all parallel lines, they never actually met the problems of living with a perceptually handicapped child.

That first group was composed of the parents of the children who were being seen in the Clinic in the special project, plus three couples whose children were enrolled in the first class for perceptually handicapped children opened that year by a newly organized special education district which covered all of the villages and school districts served by the Irene Josselyn Clinic. It met at night when the weariness

of the leader matched the weariness of the parents, at irregular intervals to fit in with a previously planned, already too-busy program of community mental health education. No fees were charged, no interviews held to determine how any one couple would fit with the rest of the group. Talks by experts in the field were interspersed with the group discussion meetings. To put it bluntly, every axiom of good group formation and planning was violated. Yet that first group had instant cohesion; the people in it cared about the subject and, almost immediately, about one another, and some even about the leader. The evaluations written by the members of that group are as open and revealing, as constructive and sensible, as any I have ever read at the conclusion of any group.

I am still not sure why this is true. Perhaps it is because most people would rather learn with a leader than from one. Perhaps my own lack of expert knowledge about the perceptually handicapped child coupled with my knowledge about "normal" children helped them to see their children and their family relationships whole. It is this supposition to which I keep returning now that I have worked with five other groups and am in the process of working with a sixth.

From the experience of these groups then, I would like to discuss formation, process, aims and evaluations.

In our experience we have found that a group should be composed only of parents whose children have been professionally diagnosed as

having a perceptual problem, and at that, one that is central to his behavior and/or learning disabilities, not one that is so peripheral to mental retardation or emotional disturbance that focusing on it will only serve to prevent the parents from confronting the other, more significant aspects of their child's difficulties. As Fritz Redl has so often said, there are styles of sickness, and in some communities at this time, perceptual handicaps are "in"; thus the importance of not opening the group to parents who have decided on their own after reading a series of articles in the daily paper that they indeed have a perceptually handicapped child. We have found that the best way to discover who these parents are is to get their names from school administrators or special personnel or, in some cases from other medical or casework agencies. The parents are told briefly of the purposes of the group. Those who choose to make an appointment for an interview to discuss joining it are thus a self-selected group. They possess enough motivation to make an appointment, keep it, and participate in an interview.

The interview serves to give the leader an opportunity to clarify the purposes, goals and limitations of the group to the parent concerned and to give information as to practical, mechanical details of its meetings. The mother (the morning hour now used limits the group to mothers) is asked, in an almost completely open-ended fashion, of her experiences with her child regarding diagnosis,

difficulties encountered, progress made, the present state of the child's academic and social status. Of course, during this process, each is evaluating the other. In a very few cases the interview has served as a real screening process, an invitation to join the group being withheld when it has been clear to the interviewer that because of personal emotional difficulties within the mother, she would not benefit from group membership and could be a destructive force within the group itself.

As the format of the groups themselves has evolved, they now meet every other week for eight sessions, for a period of one and one-half hours, in the morning--after the children have left for school and before they come home for lunch. New members are not admitted after the group has begun, although, of course, almost always other responsibilities result in a member's missing one or more sessions. A fee of \$10 is set for the usual well-documented reasons for charging for agency services, although no one is denied admission because of inability to pay. The leader comes prepared to discuss some aspect of the topic at every meeting; some days this presentation is made; sometimes the group members are so full of things they want to bring up immediately that the presentation is never made. Invariably, it is possible to weave the material to be given into the discussion itself, whether or not the formal presentation is made.

Topics which have come up, with varying emotional investment in different groups, but which have been of some concern to all are: the parent's frustration with conflicting diagnoses from various professionals, their gratitude to those professionals who finally found a correct diagnosis and worked with them, the personal impact of the diagnosis (usually one of relief that it was not a purely emotional problem caused by parental inabilities to cope with the child), the self-image of the child, familial causes, educational techniques to use, how to inform family and friends of the facts, difficulties in discipline, structure of the child's days, and specific problems of behavioral management.

The important fact is that a blueprint of what materials and concepts should be covered exists in the leader's mind. If these concepts are given in a coordinated whole or if they are brought up in answer to questions and as part of the group discussion is unimportant.

Each year one of the teachers who has worked with these children (and who now serves as consultant to all of these teachers within the earlier mentioned Special Education District) comes to the group and shows the mothers some of the imaginative and creative learning techniques and devices she has invented or adapted to help in the teaching process. Her presentation helps the parents understand the educational process and gives them hints for ways in which they

should or should not attempt to help their children in an academic way.

Group size of from ten to twelve seems best; a smaller aggregation does not become a group; a larger one is unwieldy. A group has improved chances for success if the children represented are within four years or grade levels; obviously, the concerns of the mother of a first and eighth grader are quite different. Such differences can be handled and even used constructively, but they make the job of the leader more difficult. Similarly, a group where most of the parents are at the same level of knowledge or lack of it concerning perceptual handicapping is easier to lead than one where the amount of knowledge possessed before entering the group varies from none to a pseudo-professional, over-intellectualized outlook. At best, it seems that in almost every group there will be a self-appointed "teacher's assistant." One mother commented to me that perhaps the group would be of maximum benefit to one who had just learned of her child's diagnosis; I think this is a provocative idea, worthy of further testing.

I have noticed a change in the climate of the groups from the first one to the present one. Earlier, when knowledge of learning disabilities was not widespread, parents were more perplexed. In the last five years increasingly as knowledge has been disseminated through reputable agencies, schools and the mass media parents have available

to them more facts. They come to the group less perplexed; what remains is the need to sort out the validity of what they have read and learned. They come still needing support, interpretation and help.

A destructive facet of this change is seen in a few parents who want a magical remedy--sometimes promised by a particular method or by a particular group of people. Then our approach of learning, understanding, accommodating, working, seems slow and difficult. Sometimes it is rejected.

The goals of the groups are threefold: (1) to give factual knowledge about a kind of difficulty which is little understood and about which reams of misinformation, even verging on quackery, are being printed; (2) to provide a place for ventilation of feelings concerning the child, the child's handicap, and the effect of that handicap on family and community relationships and on self and family image; and (3) to provide a clearing house where useful techniques of management can be shared.

Evaluations made by most of the members of the groups so far completed indicate that these goals have been met, more successfully in the second area than in the other two, but with some degree of success in all. In operating the group, my aim has been to serve as group counselling facility, avoiding a formal "class" format and avoiding almost equally as arduously a true group therapy format.

Discussion is kept on the conscious level without probing into unconscious motives or feelings. Indeed, my practice has been to help group members refrain from engaging in such probing in the group but offering the opportunity for individual counselling when this seems needed.

In addition to the written evaluations we have received, there are three other evaluatory devices which should be mentioned. One is that several members of the groups have made voluntary contributions to the work of the North Shore Mental Health Association which sponsors the groups. Another is that members of the second group asked to form an "alumni" association. Their feeling was that they wanted to keep up with each other and with knowledge in the field and new developments in availability of community resources for their children. Underlying this desire was what one mother expressed as, "Don't leave us out in the cold, alone, again--we have to have someone to talk to." This group has been augmented by a few members from the third and fourth and fifth groups. They meet three times a year with a completely unplanned program but with the leader being present.

Perhaps there is also something evaluatory about the fact that some of these women have now found the courage to fight for the inclusion of special classrooms and itinerant teachers in their school districts--women who previously were afraid to call attention to

themselves, their children, or their problems. Perhaps too, there is evaluation at work when the leader has been asked to speak before other larger parents' groups such as this and to plan in-service training for teachers concerning the role of the classroom teacher in handling the child with learning disabilities.

Various as these groups have been, certain generalities concerning their content does emerge. This is a good place to repeat that no pattern of perceptual difficulty is like the next. The learning problems and the behavior of every perceptually handicapped child are different from that of the next. There is tremendous variation from one child to another, from one time in a child's life to another. No generalization about parents' problems is too useful. But for whatever help it may be, there are a few guideposts:

1. In giving love and affection it is only human to want it returned.

Many brain-damaged, perceptually handicapped infants seem not to want the physical demonstrations of love adults find pleasurable in handling babies. A little later he may or he may not return affection in the manner of other pre-schoolers. If his problems go undiagnosed for some time--or forever--as has too often happened in the past--parent and child become partners in a dialogue of despair--the humiliation and frustration and feelings of inadequacy each brings forth in the other feeds the other's anxieties. Love can fluctuate, and even when present, lack spontaneous expression.

2. In accepting a child as an individual with his own strengths and weaknesses, parents identify their child's progress with their memories of their own childhoods. Often they compare him with other members of their own families and with his siblings. As child development literature becomes more available and child study discussion groups spring up, more and more parents begin to observe their children against their knowledge of what is considered "average" or "normal" growth and development. None of these guideposts are available to the parents of the perceptually handicapped child. While his physical growth and emotional needs are the same, his behavior and learning are not. Familial traits may be less visible. His career does not follow the remembered paths of his parents' childhood or the course charted by the magazine writers and PTA lecturers. The parent must relate to a very "different" child. His own maturity and the maturity of the marital relationship itself is put to a test, a test which is often passed with such success as to engender awe and admiration on the part of professionals, and is sometimes failed, tragically.

3. Because of his perceptual difficulties, it is often a frustrating task to find out just what a child's potential really is. Reading problems interfere with performance on the usual tests and with the process of evaluating school achievement. Expert psychological help is needed to determine what can and can not be expected of the child. Some with perceptual handicaps do well to complete junior high school work;

there have been a few who have attained advanced degrees in college. Usually, the more abstract school work becomes, the more difficult it is for the perceptually handicapped child to master.

4. In an era when parents have been beset with advice that to discipline a child is to stifle his creativity, told that to frustrate a child will cause him untold despair in adult life, and then later advised just as strongly to limit a child's aggression lest he think this is a world in which there is no order, most parents are confused about the matter of setting limits. The parent of the perceptually handicapped child is more confused. His child has more frustrations and fewer satisfactions. In moments of acceptance, he wants to make it up to him; in moments of discouragement he wants to punish him for what he has done to the family unit. The more obvious and serious the child's difficulties, the more extreme are these emotions liable to be. In a condition where there is such tremendous individual variation in behavior, the parent almost always needs expert help in deciding where limits shall be set and what proper methods of discipline are. At best, it is a trial and error process. The one certainty is that in order to become an acceptable member of society, the child must know there are some limits and must learn to control his behavior so that he is acceptable in some social situations outside the home.

5. Most people need home as a place to share both their victories and their disappointments. Children especially need this fortress in

the juvenile battleground where little quarter is given; children are notoriously cruel to one another. Unless guided wisely, they are particularly so to the "different" child; this is true even of the sensitive child who would like to befriend another child who needs him. The problem is that the perceptually handicapped child often "looks like anyone else"--his trouble doesn't show. Often the brain-injured child of normal or high intelligence becomes aware before his parents do of the fact that he is different. Other children make him aware of it. Their noisy rowdiness upsets him; the rules by which they play their complicated games evade his concentrated efforts to master them; his frustrations may cause him to strike out at others; his learning difficulties make others label him "dumb" when he knows he is not. Such a child may crawl back home seeking a place for his anger to spill over; he may go there looking for a soft voice and a soothing hand to reassemble the elements of his self respect. His parents are faced with the necessity of providing this haven, and at the same time of not making it such a comfortable one that it is not worthwhile to leave it in order to seek companionship of his peers. The child needs help in acquiring defenses against the rejections he is almost sure to suffer; he does not need pity or the gratification of every whim. Praise and rewards for achievements are important; the promise of them before a task is attempted only increases the pressure the child feels.

Discussion of these and many other matters has arisen in each

group. The discussions have affected each group member in an individual fashion. Typical of the expression of these effects is the following quotation from an evaluation sheet:

"In the beginning when our group just began, I found I had a problem not nearly as hopeless as I had come to believe it was. I have never been able to discuss Jack's problem with many people because he was an 'extreme' in all areas and I had nothing in common to discuss or compare. I have found I can help others with a similar problem. I felt several times that what I had said was a help to another member of the group.

The education of these children is a great problem. I feel we could do much more in this area. Learning how a child with this problem has to be taught made me very impatient with Jack's teacher and his particular classroom situation. However, it made me very aware of how important the right schooling is and because of it I could spread the word and do some constructive work in the right direction.

I still believe even more important than the proper education is the emotional development of our children. This area was one that could have been brought out more, at least for me. I feel quite inadequate at deciding the proper discipline and limits to use. Having a child with this handicap living with other children in the home can be difficult and I would appreciate advice on how we can fit these children into the family life with less tension. This was the one area I felt was

overlooked. I was the only one, I guess, with a pre-teen age child, this in a normal child can be a hectic time. I found with Jack it is much more difficult than it was with an average child with no problems other than the normal ones a teen ager can present. It could be a help to the others with younger children to be aware of what is to come. I know I could have been more effective and more understanding with some preparation and some thought given to the problems before they occurred.

Other than the obvious benefits of learning some of the facts and methods of teaching and diagnosing, etc. the greatest benefit was the opportunity to talk and air views and help and be helped in a group where we were all the same. I can get very frantic some days living with these children and it was a good release for me.

I really found the group and you a great help. I really hope we can go on where we left off; I know there is more to learn and the more we learn and the more in touch we are, the more we can help the children."

An evaluation such as this--and the many similar ones I have in my files--including those with more suggestions and criticisms--lead me to believe that the need for such group counselling of parents of brain-damaged children is present and will be with us an unpredictable length of time.

If we accept this premise, the next problem is to find and train

potential leaders for such groups. They might be drawn from the ranks of special education teachers, social workers and educators in the community. The task of finding and training such persons is a challenge which needs to be met after the challenge of diagnosis and educational planning for the children themselves is under way in any community. Perhaps our experience will help those in other areas. More useful will be sharing of experiences between various leaders who set out to work with parents. Each leader will develop his own style, each group will reflect some facets of the leader's personality. What is indispensable is a grounding in normal child development, discussion leadership skills and objectivity. What must be added earlier than I was able to add it in what was to us a "pioneering effort" is a general knowledge of the causes and results of perceptual handicapping.